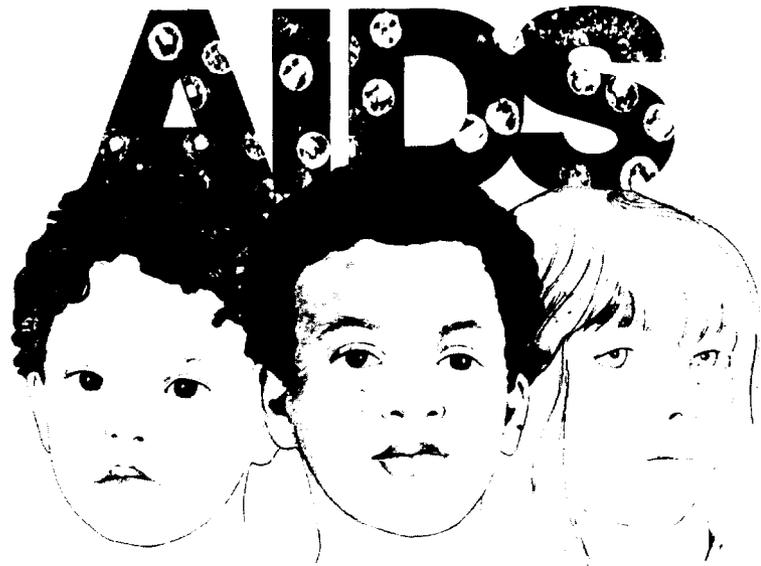


"I am the Surgeon General of the heterosexuals and the homosexuals, of the young and the old, of the moral or the immoral, the married and the unmarried. I don't have the luxury of deciding which side I want to be on."

–C. Everett Koop
The Washington Post Health Magazine
24 March 1987

Report of The Surgeon General's Workshop on Children With HIV Infection And Their Families



Presented by the
U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service
Health Resources and Services Administration
Bureau of Health Care Delivery and Assistance
Division of Maternal and Child Health

In conjunction with
 The Children's Hospital of Philadelphia

April 6th-9th, 1987

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This book is dedicated to the memory of Samuel Jared Kushnick in testimony of how much “his life has counted” and how well “his voice is heard.”

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Children with HIV Infection and Their Families
was supported by grants from
The Division of Maternal and Child Health—Public Health Service
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The photograph of the AIDS virus used in the logo was taken by Mr. Robert J. Munn, Department of Pathology, School of Medicine, University of California, Davis, CA 95616

PREFACE

This Surgeon General's Workshop on Children with HIV Infection and Their Families provides an opportunity to summarize the current knowledge about AIDS (Acquired Immunodeficiency Syndrome) in children and to make recommendations about future directions in research, prevention, and amelioration of the effects of pediatric AIDS. Surgeon General's Workshops, of which this is the fifth, have been useful vehicles for assembling experts to improve the health of mothers and children. Representatives of major professional and voluntary organizations and from various components of the Department of Health and Human Services insure not only a comprehensive coverage of the subject but also a network to disseminate and implement the recommendations.

In the early eighties we realized that children could develop AIDS when it became apparent that this then very mysterious disease could be transmitted by blood transfusions and the administration of blood products to treat hemophilia. Initially it was difficult to distinguish this entity from the rare and puzzling congenital immunodeficiency diseases in children.

By 1984 the numbers of children with AIDS had begun to escalate, especially in New York City, Newark, and Miami. The Division of Maternal and Child Health first held an ad hoc meeting to try to delineate the nature of the problem in NYC where infants were occupying acute care hospital beds unnecessarily because no alternative living arrangements were available. DMCH joined other departmental groups in cosponsoring the first National Meeting on Pediatric AIDS in November, 1984. Attendees at this meeting agreed that AIDS *did* occur in children, that the number of children involved was undercounted in the CDC surveillance system, and that infected infants and children and their families were subject to discrimination and sometimes barred from basic services. Participants expressed concern about seemingly insoluble problems, although some told of initial efforts to solve them.

DMCH, the New York State Health Department, and the Albert Einstein College of Medicine cosponsored a second National Pediatric AIDS Meeting held in March, 1986. A larger group—predominantly of physicians but also of other health workers, child welfare workers, and educators—exchanged information about the clinical spectrum and treatment efforts. A new confidence resulted from the increasing knowledge about the etiology and transmission of AIDS. We recognized that many generic solutions were applicable to HIV infection. Many could remember when most infections could be managed even without vaccines and antibiotics. It has been especially heartening to hear how the State Health Department, the Hemophilia Treatment Center, and the local school had worked together in Swansea, Massachusetts, to retain a boy with AIDS in school in a manner that evoked the best instincts of his classmates and their families.

This, then, is actually the third national meeting on pediatric AIDS, and is conducted as a Surgeon General's Workshop to bring our best efforts to bear against this new disease.

C. Everett Koop, M.D., Sc.D.
Surgeon General

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WORKSHOP PROGRAM

Monday, April 6, 1987

	Plenary Session The Children's Hospital of Philadelphia
Greetings	John Hutchings, M.D. Assistant Director Division of Maternal and Child Health Department of Health and Human Services Rockville, MD
Presiding	Stanley A. Plotkin, M.D. Director, Division of Infectious Diseases The Children's Hospital of Philadelphia
Welcome	Edmond F. Notebaert, President and Chief Executive Officer The Children's Hospital Foundation The Children's Hospital of Philadelphia
	Robert Zimmerman, M.P.H. Acting Deputy Secretary for Public Health Programs Pennsylvania State Department of Health
	Harriett Williams Deputy Commissioner for Community Health Services City of Philadelphia
Keynote and Charge	C. Everett Koop, M.D., Sc.D. Surgeon General Public Health Service Department of Health and Human Services
Global Epidemiology	Thomas C. Quinn, M.D., M.S. National Institute of Allergy and Infectious Diseases Associate Professor of Medicine Johns Hopkins University, Baltimore, MD
The Human Immunodeficiency Virus	Wade P. Parks, M.D., Ph.D. Director of Pediatrics Division of Immunology and Infectious Disease University of Miami School of Medicine Miami, FL
Immunology of HIV Infection	Arthur J. Ammann, M.D. Director, Collaborative Research Genentech, Inc. South San Francisco, CA
Epidemiology and Transmission of Pediatric Infection	Martha F. Rogers, M.D. AIDS Program/Center for Infectious Diseases Centers for Disease Control Atlanta, GA
Approaches to Prevention of HIV Infection	Walter R. Dowdle, Ph.D. Acting Deputy Director (AIDS) Centers for Disease Control Atlanta, GA
Natural History of HIV Infection I	Gwendolyn B. Scott, M.D. Associate Professor of Pediatrics Head, Division of Infectious Disease and Immunology University of Miami School of Medicine Miami, FL
Natural History of HIV Infection II	James Oleske, M.D. Associate Professor Department of Pediatrics College of Medicine and Dentistry of New Jersey Newark, NJ

Tuesday, April 7, 1987

	Plenary Session Continued
HIV Transmitted by Blood Products	Margaret W. Hilgartner, M.D. Professor of Pediatrics Director, Division of Pediatric Hematology/Oncology New York Hospital-Cornell Medical Center New York, NY
Supportive Treatment of Pediatric HIV Infection	Arye Rubenstein, M.D. Professor of Pediatrics, Microbiology and Immunology Albert Einstein College of Medicine of Yeshiva University Bronx, NY
Drug Abuse and Women's Medical Issues	Constance B. Wofsy, M.D. Co-Director, AIDS Activities Principal Investigator, Project AWARE San Francisco General Hospital San Francisco, CA
Education to Prevent HIV Infection	Karolynn Siegel, Ph.D. Director of Research Department of Social Work Memorial Sloan Kettering Cancer Center New York, NY
Legal Issues	Harold M. Ginzburg, M.D., J.D., M.P.H. Chief, Epidemiology Branch AIDS Program National Institute of Allergy and Infectious Diseases Bethesda, MD
Management of Children with HIV Infection	Mary Boland, R.N., M.S.N., C.P.N.P. Director, AIDS Program Children's Hospital of New Jersey Newark, NJ
Vaccine Strategies	Gerald V. Quinnan, Jr., M.D. Division of Virology Office of Biologics Research and Review Center for Drugs and Biologics Food and Drug Administration Bethesda, MD
A Mother's Viewpoint	Helen G. Kushnick General Management Corporation Los Angeles, CA

Individual Work Groups Begin

Wednesday, April 8, 1987

Individual Work Group Recommendations	Plenary Session: Work Groups' Summation and Presentation
Surgeon General's Response	C. Everett Koop, M.D., Sc.D.
	Close

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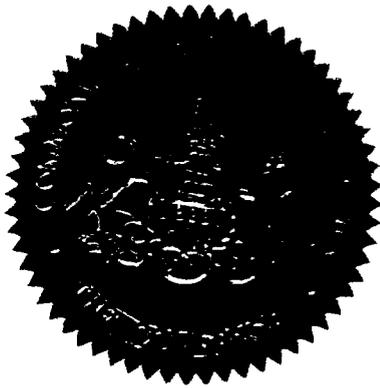
COMMONWEALTH OF PENNSYLVANIA
OFFICE OF THE GOVERNOR
HARRISBURG

GREETINGS:

As Governor of the Commonwealth of Pennsylvania, it gives me great pleasure to extend greetings to all those gathered for the AIDS workshop being held by United States Surgeon General, Dr. C. Everett Koop, M.D. at The Children's Hospital of Philadelphia.

I applaud all of you for the dedicated and professional efforts you have taken to improve and strengthen pediatric health care.

Best wishes for a productive and meaningful workshop.



Robert P. Casey
Robert P. Casey
Governor